

Abstract 594

TITLE: HIV Reporting by Unique Identifier: The Texas Experience

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ISSUE: There is general agreement on the need for HIV surveillance, but great division over how it should be done. Some advocates who are opposed to HIV reporting by name argue that non-named HIV reporting offers the advantages of providing information on HIV disease while offering a shield of anonymity to the patient. Until recently, there were no data available on the performance of non-name-based systems of surveillance for HIV.

SETTING: HIV/AIDS surveillance and HIV testing provider settings

PROJECT: Texas used a system of non-named HIV surveillance from 1994-1998. HIV infections were reported by providers and laboratories using a 12-digit code: last four digits of the social security number, date of birth, and indicators of race/ethnicity and sex. Evaluation of the system focused on completeness of reporting elements; completeness of reporting; ability to unduplicate data across AIDS and HIV databases and match HIV data to alternate records; the ability to support disease intervention efforts; and the usefulness of the data.

RESULTS: The proportion of HIV reports with complete UIs (all 12 digits present) rose from 38% for tests reported in 1994 to 85% for tests reported in 1998. This increase in item completeness was due to decreased reporting from laboratories in 1998, as laboratory reports typically had lower levels of UI item completeness. Anemic laboratory reporting was the major contributor to low completeness of reporting. Estimates of completeness of reporting suggest that between 46% and 74% of the positive HIV test results were not reported. As AIDS cases are reported by name, the ability to unduplicate across HIV and AIDS databases was limited. TDH's ability to use alternate records for HIV case finding was also limited because most of the systems routinely used do not contain the UI elements. Finally, the public health utility of the data were very limited. Eighty percent of the key local/regional health departments indicated that they could not use the UI to follow back with providers to discuss individual cases. As reports could not be linked to client records, the only information available on HIV infection were the elements in the UI, which did not include risk behavior. The anonymous nature of UI reporting made health department follow up with patients impossible, even if such follow up were desired by the provider to notify patients of test results or offer partner services TDH issued the data in a limited format, but they were not used to allocate resources or evaluate prevention and services programs.

LESSONS LEARNED: The ability of laboratories to support non-named based reporting systems is key. If laboratories cannot support non-named reporting, completeness of reporting and representativeness of reporting will suffer, thus limiting the validity of the data. States and their communities should also consider the costs of restricting follow back and disease intervention efforts for HIV.

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